

Angels at Bethesda

Angel Flight

Charitable medical air transportation serving patients of the National Institutes of Health

TRAPS Patient Says, 'You Can't Give In'



Family enjoys a good time together. R to L: Tim, Renee, son David with girlfriend, Keeleen, and Renee's niece, Ashley.

Growing up, Renee thought it was normal to feel sick to her stomach all the time.

But she knew that in other ways she wasn't like the rest of the kids, suffering as she did from high fevers and muscle pain that prevented her from playing outside with the others.

"I tried to be like them," she said.

Unsolved Riddle

Now 52, the Lansing, Michigan, woman remembers doctors treating her for pneumonia and stomach aches. But none could solve the

riddle of her painful and ongoing symptoms.

"I have the symptoms of 10 different diseases," she said. "I was tested 32 times for lupus."

Brother Steps In

Things changed when her brother got involved. David Shelton is a genetic research engineer who in 1996-1997 was working at NIH with two pioneering researchers, Dr. Francis Collins and Dr. Daniel Kastner, to study a periodic fever disease known as TRAPS.

Hard to Diagnose

The acronym stands for Tumor Necrosis Factor Receptor Associated Periodic Syndrome. "It is really hard to diagnose," Renee said.

TRAPS is clinically defined as an "autosomal dominant multisystem disorder," meaning that one parent has a genetic abnormality on a non-sex chromosome that affects multiple sites at one time.

When the marker for TRAPS

was discovered in 1997, Shelton was named in the journal article. Ironically, he himself has the disease. His and Renee's father is an asymptomatic carrier.

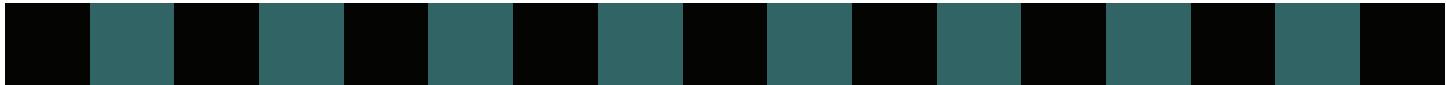
TRAPS Test Positive

Recognizing that Renee might also be afflicted, Shelton arranged to have her tested for TRAPS at NIH. Her blood was drawn and sent to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). The tests came back positive. This was in 2002.

'I Can Do This'

Renee's first thought was that she could beat the diagnosis: "I'm strong. I can do this." But when she was in so much pain she couldn't get out of bed, she knew she had to go to NIH.

There, doctors started her on Enbrel, a drug given intravenously that is a primary treatment for rheumatoid arthritis but one that has been used with success in treating TRAPS. "It's made all the difference," she said, noting that **(Continued on page 2)**



'You Can't Give In' (from p. 1)

she takes injections three times a week..

Renee and her husband, Tim, have two grown children. Her son, David, has TRAPS, but not her daughter, Monica.

Renee works for Lenscrafters as an optician and says she tries hard "to be independent. I've always worked. You can't give in. I watch other people [with the disease], and they become bitter and angry."

Angel Flight Steps Up

She's been taking flights to NIH for seven years, paying for airline tickets herself.

But last year, she was unable to afford a ticket. Marita Eddy, transportation coordinator at NIH for Angel Flight, helped to arrange a round-trip flight for her and Tim.

"It was incredible. The pilots were so good to us. One guy flew low and explained everything to us. I couldn't believe how these people stepped up." ↗



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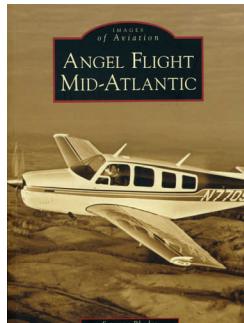
Ed Boyer

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Ed Boyer is the CEO and President of Mercy Medical Airlift, the parent organization for Angel Flight.



These two NIH patients—Cheyenne (left) and Kayle—are featured in Suzanne Rhodes' fascinating pictorial history, *Angel Flight Mid-Atlantic* (Arcadia Publishing). Order your copy today by sending a check for \$25 payable to Angel Flight and denote "Angel Flight book." Price includes S&H. Mail to Angel Flight, 4620 Haygood Rd., Ste. 1, Virginia Beach VA 23455.

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You can donate your unused frequent flyer miles to Delta, United, and US Airways?
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